



**9th Annual ALD Standards of Care Conference
W Loft - 240 Kent Ave**

Thursday, March 27, 2025

Standards of Care Conference: Day One

8:00 AM – 9:00 AM	Breakfast & Registration
9:00 AM – 9:15 AM	ALD Alliance Welcome Gerald Raymond, MD Johns Hopkins
9:15 AM – 9:45 AM	ALD Newborn Screening Roundtable Update Joseph Orsini, PhD, NYS Department of Health
9:45 AM – 10:15 AM	ALD Standards of Care: Pediatric Endocrinology Molly Regelman, MD, The Children's Hospital at Montefiore
10:15 AM – 10:45 AM	ALD Standards of Care: Pediatric Neurology Eric Mallack, MD, MBE, MS, Kennedy Krieger Institute
10:45 AM - 11:00 AM	Break
11:00 AM - 11:30 PM	ALD Follow Up Protocols at MGH Catie Becker, NP Massachusetts General Hospital
11:30 PM - 12:00 PM	The CALYX Clinical Study in cALD Ali Fatemi, MD, CMO, Kennedy Krieger Institute
12:00 PM – 12:30 PM	Progress for Women with ALD: Identifying Unmet Needs & Neurological Disease Burden Elle Winter, Mass General Hospital
12:30 PM – 1:30 PM	Lunch Break

- 1:30 PM – 2:00 PM **ALD Newborn Screening Parent Perspective**
Ashley Brennan, New York
- 2:00 PM – 2:30 PM **A Mouse Model for Cerebral ALD Opens New Doors for Therapy Development**
Keith Van Haren MD, Stanford University
- 2:30 PM - 3:00 PM **ALD Newborn Screening State Experience: Colorado**
Erica Wright, MS, CGC, University of Colorado Medicine
- 3:00 PM - 3:30 PM **Navigating Insurance**
Lisa Eisenbud, Boston Children's Hospital
- 3:30 PM - 4:00 PM **Supporting the Siblings: Managing a New Normal & Caring for our Community's Siblings**
Sarah Stoney, MSW, LSW, Children's Hospital of Philadelphia
- 4:00 PM - 4:30 PM **Leukodystrophy Care Network**
Anna Grantham, Hunter's Hope

Friday, March 28, 2025

Standards of Care Conference: Day Two

- 8:00AM – 9:00AM Breakfast
- 9:00AM – 9:30AM **ALD Newborn Screening State Experience: Maryland**
M Christine Dorley, PhD, Maryland Department of Health
- 9:30AM – 10:00AM **ALD Genotype-Phenotype Associations in California NBS Populations**
Keith Van Haren MD, Stanford University
- 10:00 AM – 10:30 AM **Diffusion imaging and prognosis for neurocognitive outcomes in cerebral ALD**
Rene Pierpont, Ph.D., L.P., University of Minnesota
- 10:30 AM - 10:45 AM Break
- 10:45 AM – 11:00 AM **Update on Gene Therapy for CALD**
Rich Colvin, MD bluebird bio
- 11:00 AM - 11:30 AM **Gene Therapy for C-ALD**
Tim Olson, MD, PhD, Children's Hospital of Philadelphia
- 11:30 AM - 12:00 PM **Navigating Uncertainty in Cerebral ALD: Neurological Outcomes and Risks of Treatment**
Florian Eichler, MD, Massachusetts General Hospital
- 12:00 PM - 12:30 PM **Gene Therapy: A Parent's Personal Experience**
Richelle Brooks, New York
- 12:30 PM – 1:30 PM Lunch Break

1:30 PM – 2:00 PM	Transition of Care for ALD Pediatric Patients Molly Regelmann, MD, The Children's Hospital at Montefiore
2:00 PM - 2:30 PM	ALD Newborn Screening Parent Perspective Kayla Rennie, Pennsylvania
2:30 PM – 3:00 PM	Highlights from ALD Alliance New York Metabolic Center Tour Miranda McAuliffe, ALD Alliance
3:00 PM - 3:30 PM	Imaging Iron and Myelin in ALD Eric Mallack, MD, MBE, MS, Kennedy Krieger Institute
3:30 PM - 4:00 PM	Eradicating Death by Zip Code: RUSP Coalition Efforts Rose Gallagher, Travers Therapeutics

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